

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1730001

Exhibits: WITN1730002- WITN1730006

Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B but I am known as GRO-B of GRO-B GRO-B I was born on GRO-B I was widowed at GRO-B years old and currently live with my GRO-B GRO-B and my new partner who moved in with me in 2018. I work part time as a GRO-B
2. I make this on statement in relation to my late husband, GRO-B: H who was born on GRO-B and passed away, GRO-B I met H online when I was living in GRO-B I moved to the UK in GRO-B and married H 3 months later.
3. I have no family here aside from my in laws who have been very good to me. My mother-in-law, GRO-B and I were very close, but unfortunately she passed away about GRO-B years ago.

4. This witness statement has been prepared without the benefit of access to my late husband's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

**Section 2. How infected**

5. [H] suffered from mild haemophilia A. He used to go his local haemophilia centre with his mother to receive Factor VIII treatment. He was advised that if he had a bleed he should go to Lewisham Hospital, London to stay on the safe side. His mother told me that before she and [H] arrived at hospital, the treatment would be ready and even if it was not necessary, it would be administered to him. My mother-in-law was a carrier and out of her [GRO-B] [H] [GRO-B] and [GRO-B] though it was only [H] who passed away as a result of contaminated blood.
6. In [H]'s younger years, he was treated at Lewisham Hospital, London, however, he moved to Addenbrooke's Hospital in Cambridge where he was under the care of [GRO-B] HIV Consultant and [GRO-B] Hepatologist Consultant. I cannot say much about treatment in his early years as this was before I entered my husband's life and his mother has passed away. When I arrived in the UK, [H] only ever went to Addenbrooke's.
7. As a result of receiving contaminated blood products in the 1980s, [H] was infected with HIV and Hepatitis C. I cannot say for certain when he was first tested positive, but my husband believed that his mother found out when he was around five years old; however, she only conveyed the news to him when he turned thirteen. My husband drafted many notes and a list of questions he wanted answered prior to his death in preparation of an Inquiry, if there was ever to be one, which I attach at Exhibit WITN1730002.

8. The Hepatitis C completely damaged my husband's liver. Consequently he received a liver transplant in [GRO-B] After receiving the transplant, unfortunately the Hepatitis C returned and destroyed his new liver as well [H] died from lymphoma and complications caused by both HIV and Hepatitis C.
9. [H] also had Hepatitis B.

### Section 3. Other Infections

10. I remember that [H] received a letter describing that he may have vCJD. He did not know what to do when he received that letter. It was very scary and on top of everything else, this was the last thing we were concerned with.

### Section 4. Consent

11. [H] believed that when he was younger, Factor VIII was administered to him without his or his mother's consent. He would merely be given it because of the fact that he had a bleed and was present at the hospital. They never properly assessed whether there was an actual need. I believe that he was over medicated.
12. My mother-in-law must have trusted the hospital staff and believed that they would be doing the best for her child. She was under the assumption that they knew what they were doing and that he would have been safe with them. She assumed he was being given the treatment as he needed it, but obviously they never considered the need prior to administering Factor VIII. My mother-in-law prepared a statement around the time of the Archer Enquiry in 2006 which I attach at Exhibit WITN1730003.

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13. I do not know if my mother-in-law was ever asked for consent prior to my husband being tested for HIV or Hepatitis C. When they conducted such tests, I do not know if it was done with her knowledge.

14. In terms of whether he was tested for research purposes, [H] always said to me that he believed that the Factor VIII was being used on haemophiliac children to test its benefits. He felt that he was one of these children.

### Section 5. Impact of the Infection

15. For [H] things were extremely difficult. He would have good days and bad days. Before I came into his life, he never had another relationship so he was very much looking forward to me coming over. It gave him hope. After arriving, [H] would often be unable to work as he was very tired. We took every day as it came as no two days would be the same. Sometimes, he would go through the night unable to sleep. [H] expressed his own thoughts and emotions about being infected by contaminated blood which I have previously exhibited at WITN1730002.

16. When I met him [GRO-B] he was very skinny and although he was sort of well, but at the same time, I could see that he was suffering. For the first year that we were together, every two to three months he would go into hospital overnight for a biopsy to monitor if his body was rejecting his new liver. He always lived with some form of medical complication, but he powered through and wanted to get better.

17. He underwent a liver transplant at Addenbrooke's which was performed by [GRO-B] [GRO-B]. When our daughter was born on [GRO-B] he was the happiest man alive. He could not believe that he was a father.

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18. In 2006 [H] experienced a pain in his shoulder. I called my brother-in-law who helped me take him to St Thomas' Hospital, London. Apparently he had a collapsed lung, which was the second time for him; however the first occurred before I was in his life. He had to undergo surgery and subsequently was diagnosed with Methicillin Resistant Staphylococcus Aureus (MRSA). Six weeks later, following his discharge, he grew more fatigued.
19. He was disappointed to have already missed his baby's first birthday and her first steps due to the above treatment, and after his discharge, there were things he would have wanted to do with his child that he could not, things that a healthy father would have been able to do. If we visited the park with our child, he would sit on a bench and witness other fathers running after and playing with their children. He was physically unable to do this and this made him feel very depressed.
20. In early 2008, my husband had routine appointments at Addenbrooke's every two to three months [GRO-B] discovered that the Hepatitis C had come back into his new liver. The doctor offered him some new treatment to which my husband was delighted. He was always so positive and believed that things would work out. In September 2009, he started clearance therapy for Hepatitis C. This involved Interferon and Ribavirin which had severe side effects on [H]. In November 2009, the doctor stopped this treatment as he discovered a lump on his stomach. We had planned to spend that weekend away as it was our fifth anniversary and despite the lump found, [H] insisted that we go. After our return home, his condition significantly deteriorated.
21. On 19 December 2009, two days prior to [GRO-B] my brother-in-law came around to take him to the hospital. We were told later that month by his oncologist that he had lymphoma, but that they were going to try chemotherapy. He spent Christmas of 2009 mainly in hospital for observation but

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was allowed home on Christmas Eve. Unfortunately on Boxing Day I had to call an ambulance as he was vomiting blood like I had never seen before.

22. At first instance we were taken to Darent Valley Hospital which did not seem to have a clue about his health issues. [H] insisted that he be taken to Addenbrooke's as he was comfortable with [GRO-B]. He therefore discharged himself and we had to move him there ourselves. He started his first round of chemotherapy on New Years Eve 2009. At first, the doctor thought the chemotherapy was working, but on the second round [H]'s kidneys started shutting down and he continued violently vomiting blood. All they could do was try to make him feel comfortable. On the [GRO-B] his kidneys stopped completely so he underwent dialysis all night.

23. I spent most of my time in hospital leaving my daughter in my brother-in-law's care [H] and I felt it was too cruel to let our child see her father in that condition. I was told to go home for a break on Saturday night and I came back on Sunday morning. My brother-in-law looked very rough and I could see he had been in tears. The doctor called me and my in laws into a meeting room where I immediately asked, "How long have we got?" [GRO-B] replied that if [H] stayed in hospital, weeks, but if he went home, days. He told us that they had exhausted all options and that [H]'s liver and kidneys has stopped functioning. He said regrettably that there was nothing more they could do for him. I asked the doctor if it was absolutely necessary to tell my husband that he would not make it. The doctor said yes. Upon finding out, [H] begged the doctor to do anything to save him. He was so desperate to stay with his family. I recall the doctor knelt before him, held his hand and said, "You've gone through so much and never complained, but there is nothing else that we can do."

24. [H] made the decision that he wanted to be at home with his daughter. On Tuesday we brought him home and his brothers said they would carry him up to

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his bedroom. He refused their assistance and insisted on climbing the stairs himself. At four in the morning [H] said that he needed to go to hospital and that he wanted to speak to his mother. I called her and the GP on his request. There was a hospice near our house and we managed to admit him there.

25. Before taking him, I got my daughter ready for nursery and told her to say goodbye to her daddy. My husband sat up and tried to look as well as he possibly could. He held his daughter and said, "Go sweetie, go and have fun at nursery and daddy will see you later." After our daughter went to nursery the hospice sent an ambulance. A nurse took my hand and told me that [H]'s breath was getting shallower and shallower. I said my goodbyes to him at the hospice and he was gone that afternoon.

26. My husband took antidepressants before I came to the UK, but stopped these after I arrived, He was so grateful to have me and his daughter in his life, but his life alternated between home and the hospital and it should not have been like that. This depressed him very much. If he had not been infected, he would have only needed to go in for haemophilia treatment.

27. I strongly believe that my husband's schooling was affected by his infections. When [H] started secondary school, it he later found out that the Head Master had announced in assembly, in front of the entire faculty, that [H] was infected with HIV. His classmates were always gossiping about it. As a result [H] was always self-conscious and uncomfortable thinking about why other people were looking at him. I was disgusted when I heard about it. The school would choose children who had the best chance of excelling in subjects and as a result of his infections, it was decided that [H] would have no chance. Because of the stigma [H] hardly had any friends [H] must have felt like he had no qualifications and no standing in society, that he only had the infections and that he would die alone.

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28. I briefly mentioned that my husband wrote statements. He spent a lot of his time conducting research into his conditions and contaminated blood as he was prepared to fight for the inquiry. He had created a list of questions for submission to the Inquiry which he wanted answers to at Exhibit WITN1730004. [H] said that if anything happened to him, at the very least, he would get compensation for his wife and daughter. Deep down he knew something would happen to him and he had been suffering from these conditions from such a young age, for such a long time. After he passed away, I found a document on his computer that he wrote for. He had intended for me to open it one day.

29. After [GRO-B] was born his mood lightened but physically he was still unable to do much. In 2007, we had booked flights to [GRO-B] as I wanted to take my husband and child to my parent's house. The doctors advised that he would be unable to endure a [GRO-B] I had to go leaving him behind. We never had the chance to go on a family holiday and [H] was heart broken. Whilst I was away, it was very hard for me as I was constantly worrying about him. Thankfully, [H]'s mother was still around and his brother [GRO-B] lived fairly close by and they would check up on him.

30. [H] [GRO-B] and I found myself having to be his carer as he was not well or fit enough to do anything for him. I had no choice but I just got on with it. I had to ensure the house was well kept, that he did not miss his appointments and that he took his medication. I did not mind doing this, but [H] was far too young to need a carer. Had it not been for the contaminated blood, he would have been healthy. I feel we were stripped of the opportunity to enjoy our time as a newly wed couple.

31. Since [H] passed away, life has been very difficult for me. I had a [GRO-B] year old child and I was not working. It was like my life changed over night. It was very hard to accept the fact that he was no longer around; he would never walk



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through the front door again; he would never come home; and I had to tell my daughter that she had lost her father. My daughter became very clingy towards me and even now as a teenager, instead of doing things with her friends, she would rather spend time with me. I feel she is afraid that she may lose me too and I in turn feel as though I need to be there for her.

32. [GRO-B] wrote me a letter addressed to [GRO-B] which I have not given her yet which I attach at exhibit WITN1730005. To this date, [GRO-B] does not know why her father passed away. When she gets older I plan on giving her the letter which explains everything and I am thankful to [GRO-B] for being kind enough to write this for her.

33. My mother-in-law told me that having [GRO-B] ruined her life and her family. She told me that my father-in-law always got angry that he was unable to do anything about the fact that [GRO-B] were suffering and he had difficulty accepting that [GRO-B] something from no where and they ended up divorcing. My mother-in-law always thought that she was doing the right thing by putting her faith in the NHS and entrusting her children to the medical professionals. This faith was shattered after losing her son.

34. We faced many financial difficulties as after [H]'s death as all his benefits stopped including Disability Living Allowance and Carers Allowance. Our income prior to his death was approximately £2,000 per month which was reduced to £500 after his passing. I was not entitled to Widow's Allowance as [H] had not worked enough. I received only Working Tax Credits (£18 per week) and Child Benefits (£20 per week). When [GRO-B] reached five, all benefits from Income support stopped. I used to receive monthly payments of about £500 from the MacFarlane Trust but this stopped when I informed them that my new partner had moved in with me.

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35. I consider myself to be very independent and whilst my in laws were very supportive, I found it very difficult to survive. I did not want to survive off benefits, so I went back to college around [GRO-B]. [GRO-B] The following year I obtained a [GRO-B] [GRO-B] whilst working part time. I had no prior experience so finding a job was difficult and I had no assistance from anyone in finding one. Since I came to the UK, I had only been a carer and no employer was willing to give me a job until [GRO-B].

36. I only earn £826 per month after tax, as I need to work part time around my daughter. I work 8am to 4pm, three days a week. My partner is supporting me with house bills but I would not go to him for everything and certainly not for expenses relating to my daughter. [GRO-B] needs money for school trips and supplies and I would need to pull out the funds. I try my very best to give her the best life possible, and my daughter goes for [GRO-B] [GRO-B] on a weekly basis. The MacFarlane Trust payments really helped me with these expenses and we should not be in a position where I cannot support my daughter in all these activities.

## Section 6. Treatment/care/support

37. During his time at Lewisham Hospital he was not happy at all. At the hospital he felt like the [GRO-D], but he was happier at Addenbrooke's.

38. [H] used to have a care worker who would come to our home. This was like therapy but with the seclusions and being on his own for so long, it was very hard for him to socialise and see other people. He would be happy to stay at home and did not want to do anything.

39. After losing my husband I tried counselling but I could not go through with it. It was extremely difficult to talk about it and I preferred dealing with it in my own

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way. My GP offered me anti depressants, but I only took two and stopped as I did not want to go down that road. I took every day as it came and did the best I could for **GRO-B**

## Section 7. Financial Assistance

40. **H** received monthly payments of about £2,000 from the MacFarlane Trust. He also received winter fuel payments of about £500 and I received the fuel payment last in December 2018. Whenever **GRO-B** needed money for school trips or supplies, I would ask the MacFarlane Trust who would pay, but they would always require a letter explaining why monies were needed or a receipt, such as for her school uniform.
41. My husband also received a lump sum from the Skipton Fund. I believe this was the Stage 1 payment. I received the Stage 2 payment of £25,000 from them after he passed away. I got no bereavement payment thereafter. I have not been in touch since I received the Stage 2 payment.
42. **H** was already in contact with the Trusts prior to our marriage. He would have dealt with the applications. We contacted them again when **GRO-B** was born to update them of our circumstances. After his death I was paid what I was entitled to as a widow with a child. After **H** passed away we continued to receive income top up payment and Child Payment.
43. After my partner came into my life everything stopped. It was my decision to inform them that my situation had changed, but I never imagined that they would take such a drastic measure. When calculating my household income they had taken my partners income into account and decided that it was above the threshold of £19,000 pa. While I understand them taking away my money, the widow's payment, however, I believe they owed my child money. She lost her dad at the age of four. She cannot ever ask her father for money. I think this is

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totally wrong. It is true that I now have a partner; however, my daughter is by no means his responsibility. He would be happy to assist if I asked, but I would never burden him with such a thing. It is for me to care for mine and [H]'s daughter alone. I wrote to my MP and in February 2019 received a letter from EIBSS advising the reduction in payments would be phased in, however, they will still not pay Child Payment. I attach two letters describing this at Exhibit WITN1730006.

### Section 8. Other Issues

44. I do not know if my husband was a party to the 1991 Litigation or if he signed a disclaimer, but I certainly was not.

45. My husband and I found it very difficult to obtain life insurance. In addition to this, my husband was unable to travel to [GRO-B] with me, but thankfully we had travel insurance and were able to reclaim his ticket.

46. Everyone who has lost someone and has been left behind should get answers. Compensation should have been paid years ago to better these people's lives, instead of having to wait around like I did. It will never bring back my child's father, but at least she will be able to have a good life and education knowing that she is financially supported the way that she would have been had her father not died so tragically. This is such a big case, but I still feel as though nothing has been done for those bereaved.

47. [H] was a member of a couple of campaign groups and was always researching his conditions. Even in his final moments, he wanted to live on. That is why what happened to him was an absolute disgrace.

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48. I wish to remain anonymous for my daughter's sake.

49. I do not want to give oral evidence to the Inquiry.

**Statement of Truth**

I believe that the facts stated in this witness statement are true.

Signed..... GRO-B .....

Dated..... 22.04.2019 .....